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## Evaluating Community-Academic Partnerships of the South Carolina Healthy Brain Research Network

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## Abstract

Community-academic partnerships have a long history of support from public health researchers and practitioners as an effective way to advance research and solutions to issues that are of concern to communities and their citizens. Data on the development and evaluation of partnerships focused on healthy aging and cognitive health is limited. The purpose of this paper is to examine how community partners view the benefits and barriers of a community-academic partner group established to support activities of the South Carolina Healthy Brain Research Network (SC-HBRN). The SC-HBRN is part of the national Healthy Brain Research Network, a thematic research network funded by the Centers for Disease Control and Prevention (CDC). It is focused on improving the scientific and research translation agenda on cognitive health and healthy aging. Semi-structured interviews, conducted at end of year 2 of the 5 year partnership, were used to collect data from partners of the SC-HBRN. Reported benefits of the partnership were information sharing and networking, reaching a broader audience, and humanizing research. When asked to describe what they perceived as barriers to the collaborative, partners described some lack of clarity regarding goals of the network and opportunities to contribute to the partnership. Study results can guide and strengthen other public health focused partnerships.

## Keywords

partnership; Alzheimer's disease; community; aging

## Introduction

Collaborative research networks can address public health issues through long-term relationships between community partners and academic institutions (Caldwell, Reyes, Rowe, Weinert, & Israel, 2015; Wilcox et al., 2013). These types of networks are crucial for addressing health disparities (Allen, Culhane-Pera, Pergament, & Call, 2011) and should result in benefits that directly affect the community (Agency for Healthcare Research and Quality, 2002; Israel et al., 1998). Employing principles of community-based participatory research (CBPR) can enhance these networks. CBPR draws on the talents and resources of all entities involved to benefit a community as a whole through collaborative work. Ideally, all partners have equal influence over the desired research outcomes and contribute to projects and initiatives in a substantive way (Cargo & Mercer, 2008; Ismail, 2009; Israel et al., 1998; Jagosh et al., 2015; Lather, 1986; Macaulay et al., 1999).

Over time, partnerships between community organizations and academic institutions have become a more common vehicle for addressing issues across a variety of domains (Minkler & Wallerstein, 2008; Tandon et al., 2007). Collaborative research has been beneficial for incorporating community cultural values, increasing positive outcomes for communities, and establishing new policies (Jagosh et al., 2015; Jagosh et al., 2012; Macaulay, Jagosh, Pluye, Bush, & Salsberg, 2014). While many studies have explored the perspectives of academic

institutions on community-academic partnerships, less research is available that emphasizes the viewpoints of community partners (Fulbright-Anderson, Auspos, & Anderson, 2001; Rubin, 2000; Tandon et. al., 2007). The current study addresses this gap by exploring the perspectives of community partners within a subset of a national community-academic partnership that is focused on promoting healthy aging.

The Healthy Brain Research Network (HBRN) is a national network funded by the Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative, which strives to improve research and facilitate public health policies regarding cognitive aging (CDC, 2016A). Currently, six universities across the United States (U.S.) are funded as HBRN centers, all of which seek to achieve mutual goals for the promotion of cognitive health and healthy aging, with a particular focus on Alzheimer's disease (AD) (CDC, 2016B). There is critical need for more evidence-based public health research, education, and policy work related to AD. In the U.S., an estimated one in nine adults aged 65 or older currently has a diagnosis of AD (Alzheimer's Association, 2016). The complexity of issues raised by this disease, combined with its increasing prevalence due to population aging, requires an urgent response from a variety of entities. The national HBRN network aims to meet these challenges collaboratively from a public health perspective.

The network's mission is to: 1) establish and advance a public health research, translation, and dissemination agenda that promotes cognitive health and healthy aging, addresses cognitive impairment, and helps meet the needs of care partners; 2) build a strong evidence-base for policy, communication, and programmatic interventions; 3) collaborate with public health agencies and their partners to accelerate effective practices in states and communities; and 4) build the capacity of public health professionals through training opportunities. (CDC, 2016B).

The HBRN works toward this mission by partnering with stakeholders – including research collaborators, community partners, government entities, and policy makers – and emphasizing strategies for identifying and disseminating evidence-based information that is culturally relevant for diverse audiences. Specifically, HBRN Centers are engaged in work focused on action items from *The Public Health Road Map for State and National Partnerships, 2013–2018* released by the CDC and Alzheimer's Association in 2013 to help state and local agencies and their partners employ effective public health practices relating to cognitive health and impairment (CDC & Alzheimer's Association, 2013). Action item focus areas are within four public health domains: monitor and evaluate, educate and empower, develop policy and mobilize partnerships, and assure a competent workforce.

The South Carolina member center of the HBRN, established in 2014, is housed within the Prevention Research Center at the University of South Carolina's (USC) Arnold School of Public Health. The aims of the SC-HBRN are to address the goals of the national network, with a particular focus on assessing public perceptions of cognition and aging, to train graduate students to become scholars in healthy aging, to effectively communicate healthy aging research to diverse populations, and to collaborate with local partners and other HBRN centers to promote a healthy aging research agenda. Ten organizations (8 local/statewide and 2 national agencies) supported the initial SC-HBRN grant submission.

Individuals from the local and statewide organizations serve in an advisory role for the SC-HBRN and are known as the SC-HBRN partners' group. Since the grant was awarded, additional individuals from the organizations have participated in the partnership. These organizations have a common interest in alleviating the effects of AD and identifying potential opportunities to promote AD awareness and education across the state. Facilitated by the grant investigators and a project coordinator, quarterly in-person meetings are held at which 20+ community and academic partners advise and support the activities of the SC-HBRN. Regular communication in between quarterly meetings occurs via telephone conferences and email exchanges.

Prior studies have identified strengths of successful health-focused research collaboratives. Specifically, previous research emphasizes the importance of establishing trust and mutual respect among all entities of the network (Caldwell et al., 2015; Galea et al., 2001; Israel et al., 2001; Lantz, Virull-Fuentes, Israel, Softly, & Guzman, 2001; Maciak, Guzman, Santiago, Villalobos, & Israel, 1999; Parker et al, 2003; Schulz, Krieger, & Galea, 2002; Seifer, 2006; Seifer, Shore, & Holmes, 2003; Sullivan, Chao, Allen, Pierre-Louis, & Krieger, 2002), practicing equality of power and influence among the various partners (Friedman et al., 2014; Israel et al., 2001; Lantz et al., 2001), and producing direct benefits to members of the larger community (Israel et al., 2001; Israel et al., 1998; Maciak, Murray-Close, & Monsey, 1999; Seifer, 2006; Zgibor et al., 2016). Factors identified as challenging to the creation of a successful health-focused research network include the extensive time needed to communicate and collaborate effectively with partners (Caldwell et al., 2015; Ferman & Hill, 2004; Seifer, 2006), lack of trust among partners (Ferman & Hill, 2004; Fulbright-Anderson et al., 2001; Israel et al., 1998), and the contrasting agendas of individual organizations involved (Ferman & Hill, 2004; Israel et al., 1998). Through the current study, we sought to gain a better understanding of factors that lead to successful collaborations among multiple partners within a cognitive health focused group from the perspective of community partners.

## Methods

The study used data from semi-structured interviews with individuals from partner organizations to assess the strengths and weaknesses of the partnership during the first two years of the five-year grant period from a community perspective. The overall objectives of this study were to assess the following areas of the partnership: (1) collaborations with the SC-HBRN; (2) benefits and strengths of the network; (3) principal accomplishments of the SC-HBRN partners' group; and (4) areas needing improvement and recommendations for making those improvements.

Seventeen individuals from nine SC-HBRN partner organizations were contacted about this study. Ten of the 17 individuals participated in an in-person interview at their organization's worksite. Participants were recruited via email in January and interviewed in February and March of 2016. Interviews were audio recorded for accurate transcription and coding of the qualitative data. The university's Institutional Review Board approved all interview procedures and protocols.

The interview guide consisted of eight main questions with focused probes (see Appendix A for interview questions and probes). Interview questions for community partners were guided by (1) the four public health domains in *The Public Health Road Map for State and National Partnerships* (monitor and evaluate, educate and empower, develop policy and mobilize partnerships, and assure a competent workforce), and (2) adaptations of concepts (e.g., common goals, commitment to partnership, strengths and weaknesses, benefits/resources, organization roles) explored in published instruments used to assess the effectiveness of community-academic partnerships, including the Bell-Elkins' Principles of Partnership in a Community-Campus Partnership and the Wilder Collaboration Factors Inventory (Bell-Elkins, 2002; Friedman et al., 2014; Mattessich, Murray-Close, & Monsey, 2001). Also included in the assessment were items related to each partner organization's focus and alignment with the CDC's Healthy Brain Initiative (CDC, 2016A) and the mission of the overall national HBRN. Interviews were just under an hour in length. A thematic analysis was applied to the qualitative data in order to analyze and identify patterns in the data. For open coding, four authors (NS, DBF, JH, SK) independently coded two interview transcripts using the interview guide as an initial framework. The initial coding of transcripts was open, or without predetermined codes, other than the interview questions themselves (Elo & Kyngäs, 2008). Following the initial independent coding, authors discussed the codes until they reached 100% consensus on the meaning of each code. Based on this discussion, a more comprehensive codebook was developed, and all transcripts were coded by the primary author using a more stringent reading of the data. All transcripts were uploaded and organized into thematic categories using the software Atlas.ti7. Saturation, the point at which analysis of the qualitative data resulted in no new dimensions, was achieved with the 10 partner interviews (Glaser & Strauss, 1967).

## Results

### Sample

SC-HBRN partners are focused on various areas of public health and aging and represent a diverse group of organizations. The ten individuals from partner organizations who participated in the interviews have a broad range of expertise including social work and counseling ( $n=3$ ), epidemiology ( $n=1$ ), medicine ( $n=1$ ), psychology ( $n=1$ ), biochemical engineering ( $n=1$ ), education ( $n=1$ ), public health ( $n=1$ ), and communications and advocacy ( $n=1$ ). They represent nine organizations that contribute to the field of healthy aging through state level health initiatives, university health and medical programs, and aging services agencies. Their organizational interests include policy, education, workforce development/training, public health surveillance, program development, and research.

### Qualitative Findings

SC-HBRN partners openly discussed many facets that influence their work with the partnership and within their own organizations. They offered their overall impressions of the network and the network's ability to address issues related to AD. Individuals noted several benefits of belonging to the SC-HBRN partnership, including information sharing and networking at meetings and community events and reaching a broader audience with a collective message and voice. Partners overwhelmingly pointed to the SC-HBRN-hosted

Healthy Aging Forum held in December 2015 as the partner group's greatest accomplishment.

**Impressions of the Network Goals:** In discussing the functions of the SC-HBRN, there was some tension regarding the goals and objectives of the overall HBRN and the SC-HBRN. One participant stated, “we want to be one of the actors, but we have to wait to get the script.” The majority of partners viewed the HBRN as a strictly research based network and saw their organizations as the benefactors of the research. Many viewed the SC-HBRN as a more centralized entity that was dependent on directives from the funding agency and other funded network sites. This process was perceived, at times, to delay the collaborative work that the SC partners' group was able to accomplish.

**Perceived Barriers:** Partners identified and discussed perceived barriers to progress within the network and made recommendations as to how to overcome them. The most frequently mentioned barrier was not having a clear direction of how they could contribute to network activities. Many partners were eager to be involved with the network, but could not ascertain where their skills were needed and awaited directives from the leader of the SC-HBRN.

**Recommendations to Address Barriers:** Some partners discussed the importance of involving the target population, including persons with AD and caregivers of persons with AD, in the planning and delivery of SC-HBRN research and programs. This target population was considered key to “making sure that we have a good balance between policy makers and researchers and maybe even caregivers and people who are involved on the ground level, [such as] service providers.” Involving stakeholders was described as essential to the process, with engagement in both the planning and delivery of programs and research as a necessary step in building trust among the academic institution, the partners, and the communities being served.

**Perceived Benefits:** Although challenges existed, individuals offered a number of benefits from participating in the partners' group. Information sharing and networking were mentioned by most as benefits to being involved in the SC-HBRN. Meeting others with similar professional interests but distinct expertise bolstered their organization's individual missions. Some individuals reported projects that they wanted to undertake but, due to a lack of resources or expertise within their organization, had not been able to execute until now. Partners explained how limiting it would be to surround themselves only with professionals who had similar skills that they had. Members were able to gain valuable information from interacting with other partners, which has in turn facilitated their own work.

Networking was also frequently cited as a benefit, in which partners could connect to others with valuable resources in the form of skills, data, or funds to support their own efforts in healthy aging. One partner explained, “The fact that HBRN is bringing some partners that we have not had before around the table to see and meet gives us this extension of our work to other areas.” Having the opportunity for partners to share their work with a broader public through forums, meetings, newsletters, and other channels has emerged from networking within the SC-HBRN.



Some partners mentioned the importance of reaching a broad audience with their work and that the SC-HBRN partnership could aid in expanding the reach of their work both within and outside of the collaborative. As explained by one partner: “When you bring all the individual interests together, that’s how you target a broader group of people...by, again, bringing the right people to the table at the right time and to have that one vision.” The SC-HBRN provides opportunities for increased exposure to issues regarding cognitive aging.

A few partners were involved in work such as research or policy advocacy which did not directly involve the target population of those living with AD or their caregivers in their daily interactions. These partners explained the disconnect they often experience between their work and the communities that they serve. These partners credited the SC-HBRN with the ability to *humanize* their work so that “the research becomes a little bit more real” and applicable to the communities with whom they work.

## Discussion

The SC-HBRN has formed partnerships with a diverse set of organizations that have the common mission of lessening the impact of AD through increasing awareness and education. This assessment demonstrates the partners’ commitment to the mission of the network and the barriers that need to be addressed to have a more effective partnership. As presented in prior studies on community-academic partnerships, a sense of mutuality was seen as crucial to securing partners’ dedication to this network (Seifer, 2006; Suarez-Balcazar, Harper, & Lewis, 2005). Partners willingly discussed barriers to the work set forth in the SC-HBRN and recognized that determining a clear direction was a key challenge for the newly established network. As cited in the literature, without guidelines, partners may have difficulty understanding their roles within the partnership (Ferman & Hill, 2004; Meier & O’Toole, 2001; Varda, Shoup, & Miller, 2011). The findings make it evident that we need to work collaboratively with partners to develop clearer guidelines on organizations’ roles within the partnership.

Partners in the SC-HBRN identified information sharing and networking, the potential to reach a broader audience, and the opportunity to be engaged with applied research as mutual benefits that motivated their interactions within the group. In alignment with previous research on partner perspectives, our partners found the inclusion of a variety of organizations with differing strengths and expertise to be a positive aspect of the network (Ferman & Hill, 2004). Additionally, access to a larger variety of skillsets through the expertise of partners has been cited consistently as a positive aspect of community-academic research partnerships (Ferman & Hill, 2004; Lasker et al., 2001; Sclove et al., 1998). Our partners’ suggestions for improvement included providing clear deliverables and tangible results, increasing the involvement of individuals directly affected by the disease, and establishing explicit roles for the partner organizations. Previous literature suggests that having a more formalized plan, including written documents, could be a useful way to provide clarification for all partners (Ferman & Hill, 2004; Fulbright-Anderson et al., 2001). These emerging themes provide a starting point for future collaborative endeavors within the network, and can, we believe, serve as markers for emerging networks to consider in the early stages of implementation.

The SC-HBRN provides multiple areas of expertise to the mission of the network. Many partners expressed how this interdisciplinary aspect was a great benefit and strength of the work of the network and to the individual partner organizations. This is in alignment with one of the overall goals of the HBRN, “to collaborate with public health agencies and their partners to accelerate effective practices “ (CDC, 2016B). Partners envisioned the SC-HBRN collaboration as a conglomeration of many different skillsets that contribute to different aspects of the overall mission of the program. These findings are consistent with other studies (Friedman et al., 2014; Zgibor et al., 2016) that demonstrated the effectiveness of using resources and strengths of a variety of organizations in order to address a larger health issue.

Many partners explained that a clear plan with goals and objectives would help to provide the group with a course of action. References to the grant’s deliverables were made by many partners who indicated that efforts within this network must “reconcile what might be our broader/general interests against what are some very clear deliverables of the grant and of the expectations of the network.” Some partners desired “stronger engagement” to partake in collaborative projects, such as forum planning, which would be beneficial for network investigators, partners, and communities. These projects are likely to continue during the grant period. Revisiting network aims and partner roles will be an important next step for the group. These themes that emerged provide a basis for modifying and improving network activities and for providing recommendations for other networks. SC-HBRN partners recommended strengthening the network through opportunities for more active engagement, the creation of a product, and by mindfully involving the intended population, persons with AD and their caregivers, in network initiatives. The partnership is still relatively young, and projects that promote a stronger engagement and/or the creation of additional products will be forthcoming.

## Limitations

This exploratory study examines community partner perspectives on the strengths and weaknesses of the SC-HBRN community-academic partnership, which represents one site out of a 6-site funded initiative. The findings are reflective of one group and cannot be generalized to other sites or to other community-academic partnerships. In addition, while interview participants were from nine of ten SC-HBRN partner organizations, only 10 out of the 17 individuals contacted participated in the interviews. Thus, the perspectives of some individuals are not included. The remaining partners that did not participate in the study had conflicts in scheduling.

## Implications

Based on study findings, we have modified aspects of the partners’ group process and created a ‘scope of partnership work’ collaboratively with community partners. The document specifies expectations for all partners (community and academic) and how each partner contributes to the collaborative, including meeting participation, planning and implementation of specific events, and hosting of networking opportunities. Beyond our partnership, study findings will also be of value to public health practitioners, academicians,



and state and local agencies entering into community-academic partnerships. Such partnerships may be very broadly focused and long-term in nature, organized to facilitate both research and the wellbeing of communities or a specific target population. Others may be more limited in scope of work or duration of shared activity. Regardless of structure and intent, effective, mutually beneficial partnerships depend on finding common ground and engaging all involved in such a way as to further individual organizational goals as well as the goals of the partnership. Choosing partners whose missions closely align with the objectives set forth by the awarded grant will ensure continuity and lessen conflicts in the agenda setting stage. Partners may join the network after its initial inception and may need additional prepping on the network's mission and objectives.

As an entity that consists of people, a network or partnership is not always predictable and will be presented with unique challenges. The network leadership must be attuned to the nuances of their group and receptive to feedback from all members. This work is driven by intentional attention to maintaining good partner relations in support of an ongoing dialogue about the benefits, accomplishments, barriers, and ways to overcome barriers identified in this study.

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## Appendix A

### Partnership Assessment Interview Guide

What is your organization's focus?

- a. How has the organization's focus changed to meet the needs of the rapidly aging population?
  - b. How is your organization involved in advocacy, research, or direct services?
  - c. What populations do you primarily work with?
  - d. How does the organization engage the community?
- 2 Please describe your organization's current and past efforts in respect to healthy brain initiatives.
- a Monitor and Evaluate:
    - i. Is the organization involved in data collection and research?
  - b Educate and Empower:
    - i. How do you educate patients or caregivers?
    - ii. How do you disseminate public health information?

- c Develop Policy and Mobilize Partnerships:
    - i. How does the organization integrate cognitive impairment into state and local governments?
  - d Assure a Competent Workforce
    - i. How is the organization involved in training professionals on cognitive health?
  - e What are the organization's future goals with respect to the healthy brain initiatives?
- 3 Please describe your organization's collaborative efforts with the HBRN.
  - a. What does your organization contribute to the HBRN partnership?
  - b. What product has your organization helped to create in the HBRN partnership?
  - c. What HBRN partnership functions does the organization attend?
- 4 What are the benefits of being a partner of the HBRN?
  - a. How is the benefit connected to your organization's focus?
  - b. What types of benefits were your organization expecting when they joined the HBRN partnership?
- 5 What do you think works well within the HBRN partnership?
  - a. Why?
  - b. Has this worked well consistently? If not, why and how has it changed?
- 6 The HBRN grant is a five-year initiative. How do you envision your organization collaborating in the HBRN partnership in the future?
  - a. How do you think the partnership will evolve?
- 7 Are there aspects of the HBRN partnership that can be improved? Please explain.
  - a. How would this improve the partnership?
  - b. Has this been a consistent concern? Please explain.
  - c. How would you address this?
- 8 What do you think is the HBRN partnership's greatest accomplishment so far? Please explain.
  - a. What do you think contributed to it being a success?
  - b. Is this something that the HBRN partnership could recreate? Please explain.

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